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Commentary

This study shows that concerns about compliance with paper diaries are justified.⁵ Although patients reported high compliance, actual compliance was low and hoarding was common. The excellent compliance achieved with the electronic diary indicates that low compliance was not due to this particular sample or to an overly burdensome protocol. Overall, these results call into question the validity of paper diary records.

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Competing interests: AAS is vice-chair of the Scientific Advisory Board of invivodata, SS is a founder of invivodata, and MRH is director of scientific affairs at invivodata, which provides electronic diary support for clinical trials.

- 1 Stone AA, Turkkan J, Jobe J, Bachrach C, Kurtzman H, Cain V. *The science of self-report*. Mahwah, NJ: Erlbaum, 2000.
- 2 Gorin AA, Stone AA. Recall biases and cognitive errors in retrospective self-reports: A call for momentary assessments. In: Baum A, Revenson T, Singer J, eds. *Handbook of health psychology*. Mahwah, NJ: Erlbaum, 2001:405-13.
- 3 Shiffman S, Hufford M, Paty J. Subject experience diaries in clinical research. Part 1. The patient experience movement. *Appl Clin Trials* 2001;10:46-56.
- 4 Hufford MR, Shiffman S, Paty J, Stone AA. Ecological momentary assessment: Real world, real-time measurement of patient experience. In: Fahrenberg J, Myrtek M, eds. *Progress in ambulatory assessment*. Seattle, WA: Hogrefe and Huber, 2001:69-92.
- 5 Hyland ME, Kenyon CA, Allen R, Howarth P. Diary keeping in asthma: comparison of written and electronic methods. *BMJ* 1993;306:487-9.

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INFOPOINTS

Improving the use of clinical databases

The need for high quality clinical databases has been thoroughly documented.¹⁻³ They offer the opportunity to carry out evaluative research and clinical audit, inform the planning and management of services, and provide individual clinicians with accurate estimates of the outcome of care that can be shared with prospective patients.

Despite these potential benefits, clinical databases have generally had few supporters and have attracted considerable scepticism and criticism. Much of the doubt about their value arises from a tendency to treat them all alike. As with all forms of information or methods of inquiry, both good and bad examples exist.

In an attempt to promote both the quality of clinical databases and their use, we have created a website where visitors can find out what databases exist (initially restricted to the United Kingdom) and be provided with an independent assessment of their scope and quality. To enable us to achieve the latter, a multidisciplinary group developed and tested an assessment instrument designed to achieve three objectives—to inform potential users of a database's scope (inclusion criteria, geographical area and time period covered, and mandatory and optional variables included), how it can be accessed (contact details of custodian), and its methodological strengths and weaknesses. All this information is obtained by a trained interviewer to ensure an independent assessment is obtained.

This Directory of Clinical Databases (DoCDat) allows visitors to search for and identify databases that may be suitable for their purpose, whether that be evaluative research, clinical audit, supporting shared decision making models, or strategic planning of services. The website allows searches to be made on the basis of one or more medical conditions, a healthcare intervention, and a geographical area. The information provided on the coverage and accuracy of the identified databases enables an assessment to be made as to their suitability. The need for such a service has recently been recognised by the UK government.⁴

DoCDat provides only an overview of each clinical database, albeit one based on an independent assessment rather than on the views of the database

custodians. To delve deeper it is necessary for a potential user to find out more from the database custodian, whose contact details are provided in the DoCDat entry. While adding more databases is the top priority, it is also essential to update and maintain all the entries. This is done by requesting information of changes from database custodians as they are instituted and by an annual inquiry initiated by DoCDat staff.

Enabling greater access and use of existing clinical databases is the immediate aim of DoCDat, but another aim is to improve their quality. Our experience suggests that some database custodians have rather limited knowledge and understanding of the methodological issues relating to database quality. DoCDat aims to advise, where appropriate, on how quality can be improved. This can be facilitated by putting database custodians in contact with one another to enable practical experiences to be shared.

The Directory of Clinical Databases (DoCDat) is available at www.lshtm.ac.uk/docdat

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Competing interests: Both authors work on DoCDat and wish to see it succeed.

- 1 Pryor DB, Califf RM, Harrell FE, Hlatky MA, Lee KL, Mark DB, et al. Clinical databases. Accomplishments and unrealized potential. *Med Care* 1985;23:623-47.
- 2 McGlynn EA, Damberg CL, Kerr EA, Brook RH. *Health information systems: design issues and analytic applications*. Santa Monica: RAND Health, 1998.
- 3 Black NA. High-quality clinical databases: breaking down barriers. *Lancet* 1999;353:1205-6.
- 4 Department of Health. *Learning from Bristol: The Department of Health's response to the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995*. London: DoH, 2002 (www.doh.gov.uk/bristolinquiryresponse/).

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